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Understanding Our Users: How to Better Deliver Health Information Online to Asian Americans, Native Hawaiians, and Other Pacific Islanders

Report on Evaluation Set-Aside Project
Tailoring Web Sites for Special Populations

Office of Disease Prevention and Health Promotion
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Executive Summary

> Designers of Web sites have started to pay attention to the fact that their designs should be tailored to the cultural communities that make up their target audiences. Users have a cultural model of methodology to be employed in a given task and that this model should be taken into consideration when designing technological tools for supporting the task.
>
> —Albert N. Badre[1]

The Office of Disease Prevention and Health Promotion (ODPHP) conducted qualitative studies on healthfinder®'s American Indian and Alaska Native section and Asian American, Native Hawaiian, and other Pacific Islander section to build user-focused sites for their cultural communities.

Section 1 presents findings from user research, including "cultural usability" tests conducted between January 2003 and April 2003 to better understand online seekers of Asian American, Native Hawaiian, and other Pacific Islander health information.

Section 2 describes the specific goals of the study and the report:

- **Goal 1:** To assess the range of health information-seeking behaviors of intermediaries and individuals of Asian American, Native Hawaiian, and other Pacific Islander communities.
- **Goal 2:** To identify tasks that intermediaries of Asian American, Native Hawaiian, and other Pacific Islander communities want to accomplish on a health information Web site.
- **Goal 3:** To understand how Federal agencies can best serve Asian American, Native Hawaiian, and other Pacific Islander communities in the area of health education materials.
- **Goal 4:** To investigate the overall usability of healthfinder®.
- **Goal 5:** To understand how healthfinder® can best serve intermediaries of Asian American, Native Hawaiian, and other Pacific Islander communities.

Section 3 provides background research to better understand the diversity of Asian American, Native Hawaiian, and other Pacific Islander communities. Section 4 outlines the methods of the study, and Section 5 summarizes the results for each goal of the study. Section 6 presents recommendations based on the research results.

Appendix A provides names of intermediaries who participated in the study. Appendices B and C are tools that can be used as key building blocks for a health information Web site, especially for Asian American, Native Hawaiian, and other Pacific Islander populations.

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[1] Badre, A.N. *Shaping Web Usability: Interaction Design in Context* (Boston: Addison-Wesley), 2002.

Section 1
Introduction

The Office of Disease Prevention and Health Promotion (ODPHP) seeks to provide health information for a variety of audiences through healthfinder® (www.healthfinder.gov). Launched in 1997, healthfinder® is a portal site, linking the general public to reliable health information resources. Known for being user-friendly, healthfinder® is regularly evaluated by its users through interviews, usability tests, online comments, and expert reviews.

From August 2002 to November 2002, ODPHP conducted interviews and usability tests[2] with American Indian and Alaska Native leaders, patients, and students in Anchorage, the Navajo Nation, and Denver to identify their needs and preferences for online health information. ODPHP identified user personas and tasks that American Indian and Alaska Native populations wanted to accomplish on a health Web site. Due to the success of this model in involving the community, and developing user personas and the user task matrix in the enhancement of healthfinder®, ODPHP adapted a similar process for expanding resources for Asian American, Native Hawaiian, and other Pacific Islander populations in 2003.

Because of the diverse and multilingual needs of these populations, ODPHP decided to test the concept of delivering a searchable database of multilingual patient education materials, each paired with its English equivalent to support its use by intermediaries. Our first goal was to identify a collection of translated materials for the top nine Asian American, Native Hawaiian, and other Pacific Islander languages spoken at home, based on Census 2000 data, which are Chinese, Hmong, Khmer, Korean, Laotian, Samoan, Thai, Tongan, and Vietnamese.[3] Our second goal was to develop, with the community, a user-friendly Web portal for delivering this collection of materials.

From January 2003 to April 2003, ODPHP conducted a series of interviews and usability tests with Asian American, Native Hawaiian, and other Pacific Islander intermediaries. We received e-mail comments and suggestions and collected qualitative data on how people in these communities access health information on the Internet and how Federal agencies can best serve their communities. ODPHP collected quantitative data on what the intermediaries want to accomplish on a health Web site. Because of its limited scope, this study is not representative of all Asian American, Native Hawaiian, and other Pacific Islander peoples.

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[2] Hsu, L.D. *Understanding Our Users: How To Better Deliver Health Information Online to American Indians and Alaska Natives (Washington, DC: Office of Disease Prevention and Health Promotion), November 2002. Available online at* http://odphp.osophs.dhhs.gov/projects.

[3] Tagalog and Japanese resources were not advertised as part of our collection because the majority of Japanese and Filipinos in the United States speak English.

Section 2
Goals

Goals for the Study

Goal 1: To assess the range of health information-seeking behaviors of intermediaries and individuals of Asian American, Native Hawaiian, and other Pacific Islander communities.

- Identify who their sources of authoritative information are.
- Discover when they would use health information and why.
- Find out when they would use the Internet and why they would choose this option.

Goal 2: To identify tasks that intermediaries of Asian American, Native Hawaiian, and other Pacific Islander communities want to accomplish on a health information Web site.

Goal 3: To understand how Federal agencies can best serve Asian American, Native Hawaiian, and other Pacific Islander communities in the area of health education materials.

- Identify preferences for existing online translated materials.
- Identify preferences for creating translated materials.
- Identify preferences for visual displays of information.

Goal 4: To investigate the overall usability of healthfinder®.

- Identify differences between users' expressed preferences for seeking health information and their actual performance.
- Explore users' patterns for searching for and filtering information.

Goal 5: To understand how healthfinder® can best serve intermediaries of Asian American, Native Hawaiian, and other Pacific Islander communities.

- Validate approach of an English searchable database of multilingual patient education materials for Asian American, Native Hawaiian, and other Pacific Islander intermediaries.

Goals of This Report

This report summarizes the data we collected and provides recommendations related to improving resources for Asian Americans, Native Hawaiians, and other Pacific Islanders on a health information Web site. Specific recommendations for healthfinder® are not included in this report.

More than 60 nationalities from South Asia, Central Asia, Southeast Asia, and the islands in the Pacific Ocean have been defined by the U.S. Census Bureau as "Asian Pacific Islanders," "Asian Americans and Pacific Islanders," and most recently, in light of the *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity,* Statistical Directive 15,[4] issued by the Office of Management and Budget (OMB), "Asians" and "Native Hawaiians and other Pacific Islanders."

Asian Americans, Native Hawaiians, and other Pacific Islanders have lived in the United States since the 1800s. Together, they represent the fastest growing minority population in America. In 2000, Asian Americans, Native Hawaiians, and other Pacific Islanders combined numbered nearly 4 percent of the total U.S. population; by 2020, this number is expected to reach 6 percent.[5]

It is important to understand the different Asian American, Native Hawaiian, and other Pacific Islander communities in this country because they are not a homogeneous population. What we present here is very brief; a better understanding of the culture and history of each of these populations can be gained from reading *The New Face of Asian Pacific America: Numbers, Diversity, & Change in the 21st Century* by Eric Lai and Dennis Arguelles.[5]

Asian Americans

Nearly 12 million people identified themselves as Asian[6] in 2000, compared to 6.9 million in 1990. Compared to the total U.S. population, which experienced a growth of 13 percent in this time period, the Asian American population grew by 72 percent. Some 1.3 million Asian Americans live below the poverty line. Sixty-nine percent of Asian Americans are born outside of the United States.[5] The leading causes of death for Asian Americans are cancer, heart disease, and stroke[7] (see table 1).

[4] Office of Management and Budget, Executive Office of the President. Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity. *Federal Register* Notice, October 30, 1997. Available online at http://www.whitehouse.gov/omb/fedreg/ombdir15.html.
[5] Lai, E., and Arguelles, D. *The New Face of Asian Pacific America: Numbers, Diversity, & Change in the 21st Century* (San Francisco and Los Angeles: *Asian Week* and UCLA's Asian American Studies Center), 2003.
[6] U.S. Census 2000. Of the 12 million, 10.2 million stated that they were Asian only, whereas 1.7 million identified themselves as being Asian in combination. The 72-percent increase of 72 percent factors in people who identified themselves as Asian alone or in combination.
[7] Centers for Disease Control and Prevention, Office of Minority Health. *Asian American Populations.* Available online at http://www.cdc.gov/omh/Populations/AsianAm/AsianAm.htm.

Table 1: Ten leading causes of death in the United States in 2000 for Asian Americans
Cancer
Heart disease
Stroke
Unintentional injuries
Chronic lower respiratory disease
Influenza and pneumonia
Diabetes
Suicide
Nephritis, nephrotic syndrome, and nephrosis
Birth defects

The six largest groups of Asian Americans include Chinese, Filipinos, Asian Indians, Vietnamese, Koreans, and Japanese, and these groups comprise numerous subgroups such as South Asians, Southeast Asians, and Hapas.

South Asian Americans encompass nearly 2 million people whose origins are from Afghanistan, Bangladesh, Bhutan, India, Maldives, Myanmar (formerly Burma), Nepal, Pakistan, Sri Lanka, and Tibet.[8] Among South Asian Americans, 21 percent have no health insurance, 25 percent are limited in English proficiency, and 25 percent live in households with incomes below $25,000. South Asian languages most commonly spoken in the United States include Bengali, Gujarati, Hindi, Punjabi, and Urdu.

Southeast Asian Americans include people whose origins are from Cambodia, Laos, Thai, and Vietnam.[5] The main ethnic groups include Khmer, Hmong (from the northern mountains of Laos), Laotian, Thai, and Vietnamese. They are the largest group of refugees to come to the United States in the past 30 years and number approximately 1.5 million. Because of their refugee status, many Southeast Asian Americans face economic hardship, lack of higher learning opportunities, and lack of parental supervision due to long work hours. Many of them do not become U.S. citizens because of language barriers. Poverty rates are high with Khmer (and Hmong populations (47 percent and 67 percent, respectively).

Hapas are Asian Americans, Native Hawaiians, and other Pacific Islanders of mixed heritage. Numbering 2.1 million people in the United States, Hapas are the second-largest subgroup after Chinese. The term "Hapa" originated in Hawaii to describe those of mixed White and Hawaiian descent.[5]

Native Hawaiians (Kanaka Maoli)

Nearly 874,000 people reported being Native Hawaiian or Pacific Islander. Of this demographic group, 141,000 people identified themselves as Native Hawaiian only; they are the largest Pacific Islander group. In Hawaii, Native Hawaiians earn lower

[8] South Asian Public Health Association (SAPHA). *A Brown Paper: The Health of South Asians in the United States* (Silver Spring, MD: SAPHA), October 2002. The Executive Summary is available online at http://www.sapha.net/execsum.pdf.

incomes, hold lower status jobs, and have the highest rate of unemployment of all ethnic groups living on the Hawaiian islands.[8]

Other Pacific Islanders

Of the 874,000 people who reported being Native Hawaiian or other Pacific Islander, 398,000 people reported being Pacific Islanders only. After Native Hawaiians, the largest Pacific Islander groups are Samoan and Guamanian/Chamorro.

The majority of Pacific Islanders live in six island jurisdictions: American Samoa, the Commonwealth of the Northern Mariana Islands, the Federated States of Micronesia, Guam, the Republic of the Marshall Islands, and the Republic of Palau. These populations are diverse in language and culture.

Native Hawaiians and other Pacific Islanders tend to lag behind other races in income, median earnings, and educational attainment, especially those age 25 and older. Native Hawaiians and other Pacific Islanders also have higher rates of unemployment (10.4 percent for men and 10.9 percent for women) than the general U.S. population (5.7 percent). Sixty-five thousand Native Hawaiians and other Pacific Islanders live below the poverty line. The leading causes of death for Native Hawaiians and other Pacific Islanders are cancer, heart disease, and stroke[9] (see table 2).

Table 2: Ten leading causes of death in the United States in 2000 for Native Hawaiians and Other Pacific Islanders
Cancer
Heart disease
Stroke
Unintentional injuries
Chronic lower respiratory disease
Influenza and pneumonia
Diabetes
Suicide
Nephritis, nephrotic syndrome, and nephrosis
Birth defects

Model Community Myth

Asian American, Native Hawaiian, and other Pacific Islander peoples are often considered a "model community"—stereotyped as passive, compliant, overachieving, and without problems or needs.[10] Supporting this myth is the fact that these

[9] Centers for Disease Control and Prevention, Office of Minority Health. *Native Hawaiian & Other Pacific Islander (NHOPI) Populations.* Available online at http://www.cdc.gov/omh/Populations/NHOPI/NHOPI.htm.

[10] President's Advisory Commission on Asian Americans and Pacific Islanders. *Asian Americans and Pacific Islanders: A People Looking Forward; Action for Access and Partnerships in the 21st Century. Interim Report to the President and the Nation* (Rockville, MD: White House Initiative on Asian Americans and Pacific Islanders), January 2001. Available online at ftp://ftp.hrsa.gov/aapi/interimreport3.pdf.

populations combined continue to have the highest median household income and education compared to all other races in the United States. However, 1.4 million Asian Americans and Pacific Islanders, or 13 percent of this population, were living at or below the Federal poverty level in 1998. Two million Asian Americans and Pacific Islanders do not have health insurance; Korean Americans have the highest rate (40 percent) of noninsurance.[11] Some 17.7 percent of Native Hawaiians and other Pacific Islanders (22.7 percent for Pacific Islander children) lived in poverty compared to a national rate of 12.4 percent. Twenty-nine percent of Asian-language households were linguistically isolated—that is, all the adults in these households (high school age and older) had limitations in communicating in English.

> Underemployment . . . lack of community health care resources and external pressure in the form of neighborhood gentrification . . . linguistic isolation . . . lack of affordable housing . . . While some contemporary APA [Asian and Pacific American] communities have prospered, others face significant economic development challenges as APAs are amongst the richest and poorest, the best educated and least educated of all Americans.
>
> —Paul Ong and Doug Miller[12]

Asian American, Native Hawaiian, and other Pacific Islander communities are more vulnerable to depression and other mental health disorders due to stress related to immigration and acculturation, as well as cultural values regarding health care, disease, and family honor.[13]

Internet Use

The Pew Internet and American Life Project[14] found that 75 percent of English-speaking Asian American adults have gone online, compared to 58 percent of White adults, 50 percent of English-speaking Hispanic American adults, and 43 percent of African American adults.

With more than 5 million Asian Americans online, they are the Web's most experienced ethnic group. Seventy percent of Asian American Internet users are online on a typical day, compared to 58 percent of White Internet users. Eighty percent of Asian Americans have been using the Web for more than 2 years. In addition, Asian American users stay online longer than anyone else. Forty percent of Asian American Internet users stay online for 2 or more hours. About 15 percent spend 4 or more hours online at a time.

Lack of Internet access is a major issue for Native Hawaiians and Pacific Islanders. Efforts are underway to connect all Hawaiians who live on homestead lands.

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[11] Hurtado, M.P., Swift, E.K., and Corrigan, J.M. (eds.), Committee on the National Quality Report on Health Care Delivery, Board on Health Care Services. *Envisioning the National Health Care Quality Report* (Washington, DC: The National Academies Press), 2001.

[12] Ong, P., and Miller, D. *Economic Needs of Asian Americans and Pacific Islanders in Distressed Areas: Establishing Baseline Information* (Los Angeles: Ralph and Goldy Lewis Center for Regional Policy Studies, UCLA School of Public Policy and Social Research), July 2002. Available online at http://lewis.sppsr.ucla.edu/EDAReport.pdf.

[13] National Asian Women's Health Organization. *Empowering Avenues for Community Action: The National Collaborative for Asian American Women's Mental Health*. Available online at http://nawho.org/file_depot/0-10000000/0-10000/9950/conman/Mental+Health+Fact+Sheet.pdf.

[14] Spooner, T. *Asian-Americans and the Internet: The Young and the Connected* (Washington, DC: Pew Internet and American Life Project December 12, 2001. Available online at http://www.pewinternet.org/reports/pdfs/PIP_Asians_Report.pdf.

Health Disparities

Significant health disparities exist among Asian American, Native Hawaiian, and other Pacific Islander populations, especially in cardiovascular disease, cancer (liver, lung, nasopharyngeal, cervical, breast, stomach, and colorectal), diabetes, family violence, hepatitis B and C, HIV/AIDS, tuberculosis, mental health, and substance abuse.[15]

- Although Asian Americans represent 4 percent of the population, they account for more than half of the 1.3 million chronic hepatitis B cases in the United States.[5]
- Fifty-five percent of Tongan women, 74 percent of Samoan women, and 77 percent of men and women living in Nauru are obese.[16]
- Native Hawaiians have the highest mortality rates and the lowest life expectancy among the five major ethnic populations in Hawaii.[17]
- Asian American women over age 65 have the highest female suicide rate across all racial/ethnic groups.[18]
- Chinese, Filipino, Japanese, and Korean immigrants consistently report higher numbers of depressive symptoms than do Whites.[19]
- Analysis of data collected in Hawaii from 1996 to 2000 showed that Native Hawaiians were 2.5 times more likely than non-Hispanic White residents of similar age to have diabetes.[20]

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[15] President's Commission on Asian Americans and Pacific Islanders. As-yet untitled report, forthcoming.
[16] Pacific Islanders Are World's Fattest. *BBC News,* November 29, 2001. Available online at http://news.bbc.co.uk/1/hi/world/asia-pacific/1682477.stm.
[17] The Health of the Hawaiians: E Ola Na Kin. *Pacific Health Dialog: Journal of Community Health and Clinical Medicine for the Pacific 8(2) September 2001.*
[18] National Center for Health Statistics. *Health, United States 2001* (Hyattsville, MD: U.S. Public Health Service, Centers for Disease Control and Prevention), 2001.
[19] Hurh, W.M., Kim KC. *Uprooting and Adjustment: Sociological Study of Korean Immigrants' Mental Health, 1986-1988* (Macomb, IL: Western Illinois University), 1988. Available online at http://www.radcliffe.edu/murray/data/ds/doc1143.htm.
[20] National Institute of Diabetes and Digestive and Kidney Diseases. *National Diabetes Statistics Fact Sheet: General Information and National Estimates on Diabetes in the United States, 2000* (Bethesda, MD: U.S. Department of Health and Human Services, National Institutes of Health), NIH publication no. 02-3892, 2002. Available online at www.niddk.nih.gov/health/diabetes/pubs/dmstats/dmstats.htm (accessed May 2003).

Section 4
Study Overview

This section identifies the research audiences and summarizes the research process.

Audience

ODPHP interviewed 30 Asian American, Native Hawaiian, and other Pacific Islander intermediaries and received online comments from 108 additional intermediaries (appendix A) representing these target populations. Intermediaries were asked about their own use of the Internet as well as use by the communities they serve.

To synthesize the research findings into a useful tool for Web development, we extracted similarities to build audience profiles or *user personas*. Appendix B provides brief personas of typical Asian American, Native Hawaiian, and other Pacific Islander intermediaries, organized into the following eight categories that reflect the context in which they might use the Internet to find health information.

- Executive directors
- Health educators and social workers
- Legislative analysts
- Librarians
- Physicians and nurses
- Program administrators
- Researchers
- Traditional healing practitioners

Interviewed intermediaries were selected based on word-of-mouth recommendations from the White House Initiative on Asian Americans and Pacific Islanders and the Office of Minority Health, U.S. Department of Health and Human Services.

Other intermediaries who participated self-selected to provide comments via e-mail or an online form. The White House Initiative on Asian Americans and Pacific Islanders and the American Public Health Association's Asian Pacific Islander Caucus sent out e-mails to their listservs requesting participation.

Methods

ODPHP solicited feedback from intermediaries in three ways, as described below.

Letter. The White House Initiative on Asian Americans and Pacific Islanders e-mailed a letter via e-mail to their listservs to inform intermediaries about this project and request their participation. The main goal was to identify tasks that they might want to accomplish on a health information Web site. Between January 27 and February 19, 2003, 42 intermediaries submitted comments via e-mail to ODPHP.

Interviews. From March 17 to April 10, 2003, ODPHP conducted 30 one-hour interviews and usability tests on a prototype version of healthfinder®'s Asian American, Native Hawaiian, and other Pacific Islander section (see figure 1) with intermediary audiences. These interviews were conducted at intermediaries'

workplace environment, where they normally access the Internet. For nonlocal intermediaries, ODPHP interviewed the person over the telephone.

Online form. To validate and rank the tasks that 42 intermediaries suggested as things they might want to accomplish on a health information Web site, the American Public Health Association's Asian Pacific Islander Caucus sent a request to its listserv asking members to complete an online form. Between March 17 and April 20, 2003, 66 intermediaries (including most of the 30 intermediaries interviewed directly) submitted comments online to ODPHP. They also had the option of providing additional feedback about topics that were most important to the communities they served and identifying quality translated materials.

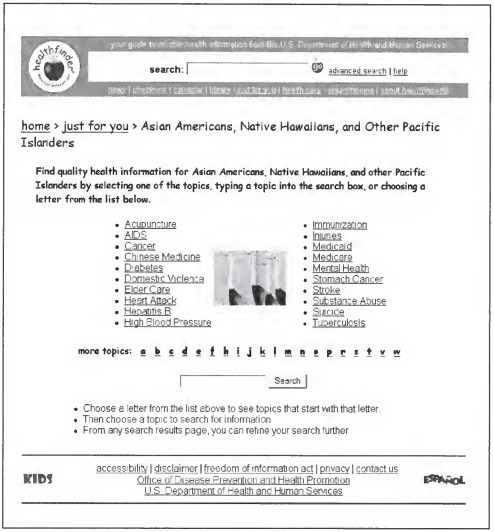

Figure 1: Prototype version tested in March 2003

Limitations of the Study

Due to limited resources, ODPHP interviewed only 30 intermediaries for this project. We did not get the opportunity to speak in person to the other respondents who contributed comments via e-mail or the online form. The following limitations were identified:

- Tasks identified by intermediaries were mixed between what they want to perform on behalf of their clients and what they want to do for themselves.
- Tape recorder documentation was incomplete for two participants.
- Views represented in this report reflect the experiences of only the 30 intermediaries interviewed.
- Interviews and usability tests were performed over the phone for nonlocal interviewees.

Section 5
Research Results

This section summarizes the results for each goal.

Goal 1: To assess the range of health information-seeking behaviors of intermediaries and individuals of Asian American, Native Hawaiian, and other Pacific Islander communities.

- Identify who their sources of authoritative information are.
- Discover when they would use health information and why.
- Find out when they would use the Internet and why they would choose this option.

Intermediaries

Most Asian American, Native Hawaiian, and other Pacific Islander interviewees used the Internet to find health information for themselves and others. All interviewees had completed a college degree, 73 percent had advanced degrees. Sixty percent used the Internet more than 2 hours per day. Those who used the Internet fewer than 2 hours a day usually requested staff to access the Internet on their behalf. Eighty percent accessed the Internet both at home and at the office. Fifty percent of those who accessed the Internet at home had broadband service. The intermediaries considered Government Web sites to be authoritative sources of information. Many used a search engine such as Google as a starting point.

Communities

Asian American, Native Hawaiian, and other Pacific Islander communities are extremely diverse. According to the intermediaries, access to the Internet directly correlated with a person's socioeconomic status. Their clients usually did not have access to the Internet because most were immigrants with low socioeconomic status. Intermediaries described how children usually accessed the Internet at school, looking up information for their parents when needed.

Intermediaries reported ongoing activities such as providing technology centers[21] where they train people how to use the computer and the Internet. They also donate refurbished computers to people who finished the course so they could continue to practice at home. In Hawaii, there is an ongoing effort to link all Hawaiian homesteads by providing a computer for every Hawaiian family.[22] Also, some community clinics such as the Wa'anae Coast Comprehensive Health Center have Internet cafés for their patients.

Most of the time, intermediaries received phone calls from community members asking them to locate health information or services on their behalf. Although the Internet might be the first source of information for intermediaries, most of the time they were disappointed by the lack of quality translated materials.

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[21] Nguyen, Thang. Interview by Leslie Hsu. Tape recording. Arlington, VA, March 20, 2003. Allen, Magaret. Interview by Leslie Hsu. Tape recording. Stratford, WI, April 3, 2003.
[22] Spoehr, Hardy. Interview by Leslie Hsu. Tape recording. Honolulu, HI, March 25, 2003.

Some intermediary organizations, especially those that provide health care, developed their own health education materials, translating Government or hospital materials into multiple Asian American, Native Hawaiian, and other Pacific Islander languages. When they received requests for health information materials in these languages, they usually looked in-house and then to their partner organizations before researching the Internet or library.

In partnership with Asian American, Native Hawaiian, and other Pacific Islander organizations, libraries have experimented with kiosks for print materials set up in grocery stores, temples, and apartment complexes that are heavily populated by Asian communities. One interviewee describes the problems they've experienced.

> We had one placed at a Vietnamese Buddhist temple, and when we went to do a site visit last year, the monks had placed the kiosk outside on the porch in the weather. We are supposed to have someone on staff there [where the kiosks are located] who will alert us if the paper kiosks are running low of materials. That's never happened. One person did mention that perhaps the Asian community is scared to take the brochures thinking they are going to be charged to pay for them.
>
> —Adela Calbillo, Texas Medical Center Library

This library subsequently experienced greater success with electronic kiosks in which an evaluation system recorded what people were looking at, what language they were looking at, and what they printed. Users were also given the opportunity to rate the materials they find. To date, the results have been positive.

Despite these attempts to help the community access the Internet, the intermediaries reported that the immigrant population received health information primarily through word-of-mouth.[23] Family members or friends read about a health issue in language newspapers they receive either from overseas or from their local community. They then talk about it over meals or during a haircut.

One intermediary discovered that language newspaper reporters helped to perpetuate myths in their health news stories. Reporters appeared to have interviewed community health center staff members who were fluent in their native language and therefore usually trained overseas. Unknowingly, these foreign-trained staff persons tell reporters false health facts, which were then printed in the very newspapers on which the community relied for health information.

Perceptions of Health

The National Heart, Lung, and Blood Institute, in partnership with the Asian Pacific Islander American Health Forum, conducted focus groups and key informant interviews with Cambodians, Filipinos, Native Hawaiians, and Vietnamese Americans. The Vietnamese[24] community believes that good health means living without pain and being emotionally stable. Health is a blessing from God, and people often

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[23] Hsu, L.D., et al. Student Leadership in Public Health Advocacy: Lessons Learned from the Hepatitis B Initiative. *American Journal of Public Health*. August 2003 (in press).

[24] National Heart , Lung, and Blood Institute. *Cardiovascular Risk in the Vietnamese Community: Formative Research From Houston, Texas* (Rockville, MD: U.S. Department of Health and Human Services, National Institutes of Health), March 2003. Available online at http://www.nhlbi.nih.gov/health/prof/heart/other/vietnamese.pdf.

meditate, practice yoga, or pray to maintain a healthy mind and body. The Filipino community believes that good health is achieved through balance among mental, emotional, and physical states of mind.[25]

> They don't talk about health issues because these issues are personal and private. They believe if you have good karma then you have good health. If you are afflicted with cervical cancer, then that means you must have been a bad woman, not in this life but in previous lives.
>
> —Dr. Thang Nguyen, Boat People SOS

> I'll give one example in the treatment of high blood pressure. A health care provider must be aware that health is often perceived of as an absence of pain in the Asian culture. Therefore, from the perspective of an Asian patient who has high blood pressure, the patient may think that they were completely healthy, until they saw the doctor who made them sick by starting them on medicines and giving them a diagnosis.
>
> —Dr. Ming-Hui Chen, Former Medical Director, South Cove Community Health Center

Most immigrants believe in myths they learned in their home country. For example, people from China believe that children inherit hepatitis B from their mothers and that the disease is transmitted through food and water. Neither of these myths is true: children have a 95 percent chance of developing immunity to hepatitis B through vaccination at birth and the disease is transmitted through blood and sexual fluids only. Focus groups and surveys conducted in several hepatitis B outreach programs around the Nation have demonstrated that these myths are widely believed in the Asian American, Native Hawaiian, and other Pacific Islander community.[26]

Native Hawaiians base their concepts of health and wellness on relationships with natural elements, natural environments, specific places, other living things, and people. These relationships form the Hawaiian concept of *ola*, built upon a strong spiritual foundation. Traditional Hawaiian healing practices are a central part of Native Hawaiian life. They include both physical and mental health interventions.[27]

Goal 2: To identify tasks that intermediaries of Asian American, Native Hawaiian, and other Pacific Islander communities want to accomplish on a health information Web site.

To achieve this goal, ODPHP collected 32 tasks identified by 42 intermediaries who responded to the letter from the White House Initiative on Asian Americans and Pacific Islanders. Through an online comment form, 66 intermediaries subsequently ranked these 32 tasks on a scale of 0 to 3, with 0 being that they would never try to accomplish this task on a health information Web site and 3 being that they always will try to accomplish this task on a health information Web site.

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[25] National Heart, Lung, and Blood Institute. *Cardiovascular Risk in the Filipino Community: Formative Research From Daly City and San Francisco, California* (Rockville, MD; U.S. Department of Health and Human Services, National Institutes of Health), March 2003. Available online at http://www.nhlbi.nih.gov/health/prof/heart/other/filipino.pdf.

[26] *The Hepatitis B Initiative* Web site, www.hepbinitiative.org. Accessed May 28, 2003.

[27] Papa Ola Lokahi. *Native Hawaiian Health and Wellness Summit and Island 'Aha: Issues, Trends and General Recommendations*, Honolulu, March 1998.

The top three tasks identified by 14 executive directors were:

1. Search for statistics.
2. Find grant information.
3. Find information on health specific to communities.

The top three tasks identified by 11 health educators and social workers were:

1. Provide information to individuals or groups (tie).
1. Find information on health specific to communities (tie).
2. Find information on disease or condition.

The top three tasks identified by 6 legislative analysts were:

1. Gather information for a meeting.
2. Find updates on health news (tie).
2. Search for topic related to health care organization (tie).

The top three tasks identified by 2 librarians were:

1. Search for translated materials (tie).
1. Find journal articles (tie).
2. Search for statistics (tie).
2. Find organizations that work on a specific issue (tie).
2. See how many Asian sites are available (tie).
2. Find information on health specific to communities (tie).
2. Find information on treatment and management (tie).
2. Provide information to individuals or groups (tie).
2. Find information on disease or condition (tie).

The top three tasks identified by 9 physicians and nurses were:

1. Find information on disease or condition.
2. Search for statistics.
3. Print handouts for patients (tie).
3. Find information on treatment and management (tie).
3. Provide information to individuals or groups (tie).

The top three tasks identified by 13 program administrators were:

1. Provide information to individuals or groups (tie).
1. Gather information for a meeting (tie).
2. Search for statistics.

The top three tasks identified by 8 researchers were:

1. Find journal articles.
2. Find information on disease or condition.
3. Search for statistics.

The top three tasks identified by three traditional healing practitioners were:

1. Find information on traditional healing (tie).
1. Find information on alternative nutrition (tie).
2. Find information on disease or condition.

Among the most significant tasks, from the perspectives of all Asian American, Native Hawaiian, and other Pacific Islander intermediaries, were the following:

- Find information on disease or condition.
- Search for statistics.
- Find information on health specific to communities.
- Find journal articles.
- Provide information to individuals or groups.
- Find grant information.
- Gather information for a meeting.
- Find updates on health news.
- Find organizations who work on specific issue.
- Search for topic related to health care organizations.

Appendix C provides specific information on users and their tasks.

Goal 3: To understand how Federal agencies can best serve Asian American, Native Hawaiian, and other Pacific Islander communities in the area of health education materials.

- Identify preferences for existing online translated materials.
- Identify preferences for creating translated materials.
- Identify preferences for visual displays of information.

Preferences for Existing Online Language Materials

Most intermediaries spoke with great passion about the difficulties they encountered with language materials. First, quality online translated materials are scarce. Second, even quality online translated materials may not be accessible to many potential users.

> There is a quality issue and effectiveness issue. Federal agencies usually hire contractors who translate materials at a Ph.D. level and who are not familiar with the audience for consumer education materials. It would be more effective and might also cost less to hire a community based organization that has knowledge about effective messages, cultural beliefs and commonly used terminology. I have seen federal agencies spend resources to print and disseminate materials where the accents are printed alongside instead of above the characters. This is frustrating for both the federal agency who is attempting to do the right thing and it perpetuates the notion that federal agencies and programs are not culturally and linguistically competent. Many member community based organizations can't access PDF materials. We have to fax things to them.
>
> —Lisa Hasegawa, National Coalition for Asian Pacific American Community Development

Intermediaries suggested providing several options such as PDF files, graphics, or entire translated Web sites that require browsers with the language plug-in. They also preferred bilingual materials because the English version of the material can become separated from the translated materials. Community health centers especially experienced this problem as newly hired staff may continue to distribute translated materials provided by their predecessor, without knowing where the materials originally came from or what they say.

> One of the things we do at AAPCHO is create health education materials that are bilingual—both in English and the client's language. One reason we do this is because let's say someone e-mailed me a link to this Vietnamese hepatitis B material—or even worse, someone printed it out and handed it to me or our patients. I can't read Vietnamese so I wouldn't know what the material says, how reliable it is, or where it came from. If the resource is bilingual, then we don't have to worry about the English and in-language text being separated.
>
> —Jeff Caballero, Association of Asian Pacific Community Health Organizations

Preferences for Creating Translated Materials

To address the lack of quality translated materials, many intermediaries create their own translated materials. Usually, they try to locate quality English content to translate into Asian American, Native Hawaiian, and other Pacific Islander languages. The process is slow because a number of problems surface during the translation process.

> There is no standard lexicon for health words. It is extremely difficult to translate, since everyone translates differently. A term like "AIDS" has no standard or comparable or competent translation in Vietnamese. They have no concept for "hepatitis B." Sometimes it is translated as "swollen liver."
>
> —Dr. Thang Nguyen, Boat People SOS

In addition, standards and processes are lacking. Organizations have developed their own guidelines or process for translating materials. The strategies vary from beginning with an original English-language document to beginning with an original Asian American-, Native Hawaiian-, or other Pacific Islander-language document or from conducting focus groups with community members to establishing expert review teams with intermediaries.

Preferences for Visual Displays of Information

One question asked in the White House Initiative letter was "What symbols or phrases suggest health and well-being to you?" Out of 42 respondents, the top suggestions were nature, nutrition, exercise, happiness, and balance.

During our one-on-one interviews, ODPHP tested two brochure concepts developed based on the 42 comments we received from the White House Initiative letter. One brochure contained nature scenes, and the other featured photographs of Asian American, Native Hawaiian, and other Pacific Islander faces. We showed these

brochures to the interviewees interviewed locally only. Most interviewees preferred images of faces combined with images of scenes where interviewees are working with community members, such as teaching them how to use the computer or passing out fliers at health fairs. Interviewees noted that too few stock photos of Asian Americans, Native Hawaiians, and other Pacific Islanders are available on the market; therefore, unfortunately, the respondents see the same stock photos all the time. They also talked about how stock photos sometimes depict these communities as "too perfect" or looking like "movie stars."

In addition to the print materials, ODPHP tested the use of graphics on the Web site. On our prototype, the graphic on the Asian American, Native Hawaiian, and other Pacific Islander main page was an animated sequence of Asian artwork symbolizing health and longevity, donated by the Smithsonian Institution (see figure 2). Most interviewees who were born outside of the United States enjoyed the artwork, saying it was a nice touch and culturally appropriate. The Hawaiians preferred seeing Native Hawaiian crafts.

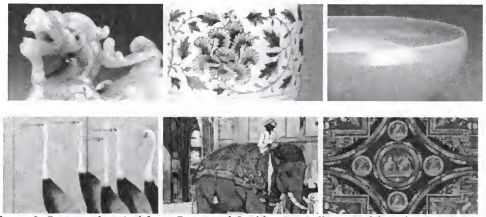

Figure 2: Images donated from Freer and Sackler Art Gallery, Smithsonian Institution

However, the images produced negative reactions from many who could not relate to the artwork:

> I don't see the relevance. Are we feeding into stereotypes? Is this the way the American society views Asian Americans and Pacific Islanders?
> —Dr. Butch de Castro, American Public Health Association's Asian Pacific Islander Caucus

Interviewees also took the opportunity to discuss the importance of using photographs of everyday Asian American, Native Hawaiian, and other Pacific Islander life in American society, instead of photographs of community members in their native dress or native countries.

Goal 4: To investigate the overall usability of healthfinder®.

During our interviews, ODPHP asked participants to accomplish specific tasks. We noted the decisions and choices interviewees made as they tried to perform efficiently. We were specifically interested in ascertaining the following information:

- Identify differences between users' expressed preferences for seeking health information and their actual performance.
- Explore users' patterns for searching for and filtering information.

Expressed Preferences Versus Actual Performance

ODPHP asked users to begin on the "Just For You" main page as this is the main entry point we are promoting to special populations (see figure 3). When users were asked to perform a task on the "Just For You" page of healthfinder®, 52 percent used the search bar, whereas 41 percent of users selected the Asian American, Native Hawaiian, and other Pacific Islander link. The remainder selected another link on the page.

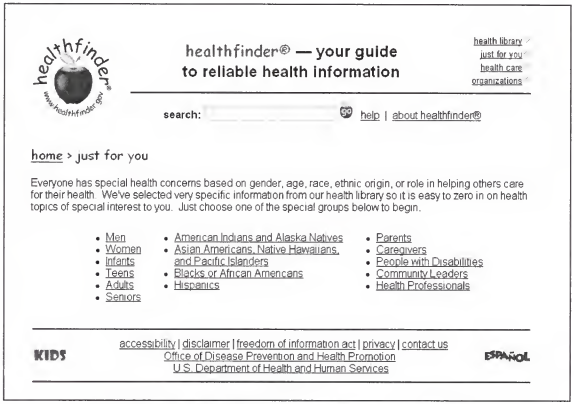

Figure 3: Screen capture of http://www.healthfinder.gov/justforyou

A majority of interviewees were pleased to see a link for "Asian Americans, Native Hawaiians, and Pacific Islanders" as opposed to "Asian Americans and Pacific Islanders." However, Hawaiian and other Pacific Islander interviewees suggested that it would still be best to disaggregate Native Hawaiians from Pacific Islanders, as well as from Asian Americans.

> It would be no different if we were lumped with Native Americans or any other ethnic group. The problem would be that we still would have the difficulty as far as interpreting what in fact are the data that relate to our communities.
>
> —Robert Uhrle, Advocate Initiatives for Grassroots Access

> If people are really honed in to their ethnicity, then you need to be able to pop up their ethnic related stuff quickly. They shouldn't have to jump through hoops to get to it. For instance, if I want to know what material you have about Native Hawaiians, show me all health-related materials you have about Native Hawaiians. I don't want to know about Pacific Islanders. I don't want to know about Asian Americans. I don't want to jump through groups to get to Native Hawaiians.
>
> —Gerald Ohta, Hawaii Department of Health

Despite the concern expressed around aggregating information for the populations, none of the intermediaries had a problem completing the task of locating translated materials on hepatitis B. The average time to complete the task was less than a minute. Those who had some difficulty locating the translated materials pointed out that the "Also available in" link was not visible to their eye because they were focused on scanning through the abstract information. They usually saw the "Also available in: Spanish" link because the link appeared much shorter and noticeable when only one language was listed. They noted that "Spanish" should not be displayed in the Asian American, Native Hawaiian, and other Pacific Islander section. Others did not see the "Traditional—Chinese" or "Simplified—Chinese" link because they were scanning for the letter "C" for "Chinese" (see figure 4).

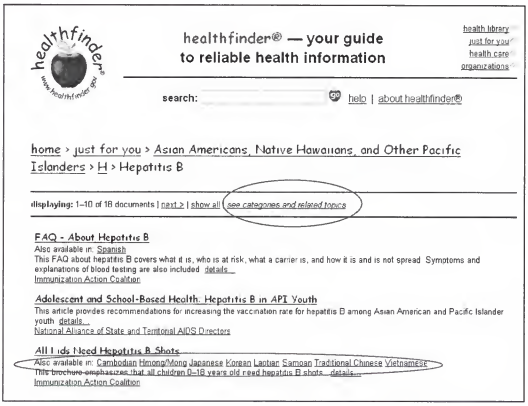

Figure 4: Screen capture of how translated materials display

The majority of interviewees did not notice the "see categories and related topics" link (see figure 4). Some suggested that the italics made the link less noticeable.

However, all the interviewees were very pleased with the choices on the "see categories and related topics" page (see figure 5).

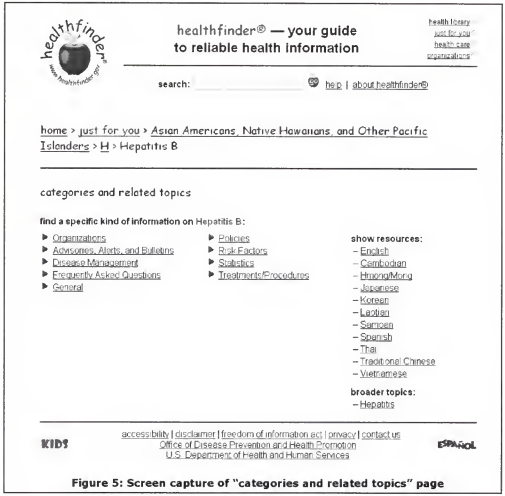

Figure 5: Screen capture of "categories and related topics" page

Interviewees were most interested in the list of languages, the "organizations" link, and the "statistics" link. They would prefer seeing these choices up front on the Asian Americans, Native Hawaiians, and other Pacific Islanders main page. The "general" link caused some confusion as users were unsure what to expect if they selected it. They also expressed a preference for the list of choices to be in alphabetical order.

The title of "show resources" and the list of languages created some confusion. Users expected the whole site to be in the language they selected. Upon selecting a language, most users said, "Oh, I got the same result as before"—meaning that they automatically assumed they were seeing the page with all hepatitis B results for Asian Americans, Native Hawaiians, and other Pacific Islanders (figure 4) instead of just hepatitis B results that had translated materials for the selected language.

> I do like the ability to click on a language. However, if someone speaks or reads only Chinese, they would not necessarily be able to read the English word "Chinese." [User selects Chinese link.] But I see now that what it does is actually provide you documents that are in the language you choose. I wish it came earlier because I would never have thought to click on "see categories and related topics." If I clicked on "Asian American, Native Hawaiian, and other Pacific Islanders," I think it would have been useful to immediately have the top documents filtered by language.
>
> —Angelo Locsin, National Asian Pacific Center on Aging

Another page that users had trouble with was the "directory of healthfinder® organizations" (see figure 6). Before seeing this page, users expressed preferences for viewing Asian American, Native Hawaiian, and other Pacific Islander organizations.

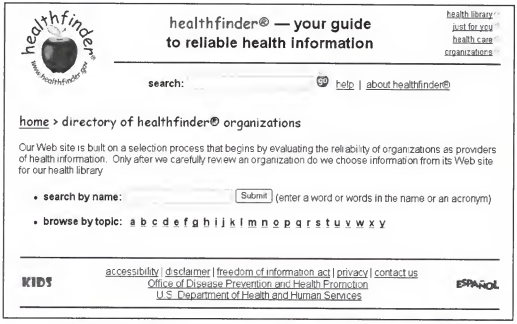

Figure 6: Screen capture of www.healthfinder.gov/organizations

After using the page, users were confused by the interface. They expected the A-Z list to be the first letter of the names of organizations—for example, "A" for "Asian Pacific Islander American Health Forum." Interviewees were all surprised to find that the A-Z list was actually a list of health topics. Some thought they had arrived at the same list they saw earlier in other parts of the site. They expressed a desire to see all organizations and be able to browse through them alphabetically or find organizations grouped by the communities they serve.

Explore User's Patterns for Searching for and Filtering Information

None of the 30 interviewees independently used the advanced search. When they were asked to view the advanced search page, some users were confused by the two search boxes appearing on the page. Others had trouble with the meaning of the titles and the drop-down menu choices (see figure 7). The choices available for

"search within" were especially confusing. Users wanted to know why you could select "documents" and "organizations" together— "Documents & Organizations"—but not all three—"news, documents, and organizations." Also, some were confused about the difference between documents and organizations.

> Search within documents, within organizations . . . what organization here, I'm not very clear about this. What organization are you talking about? Is it U.S. Department of Health and Human Services? Sort results by title. Okay, but is it title of documents or title of organization? Minor category: dictionaries are very good I think, especially to have medical dictionary for Chinese to English or English to Chinese. What is Metasite? What's the difference between Research and Clinical Trials? What's the difference between self-help and quick tips? What's a test?
>
> —Dr. Weidong Lu, Dana-Farber Cancer Institute

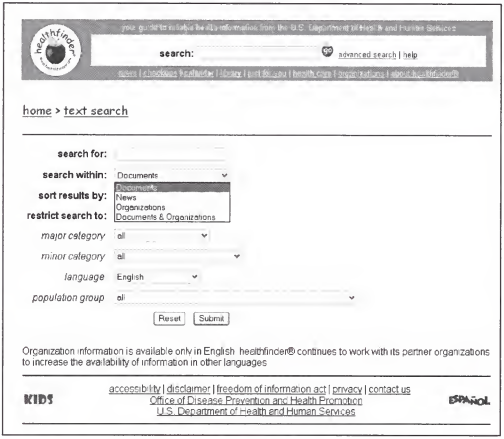

Figure 7: Screen capture of advanced search options

All interviewees were extremely interested in being able to search for a specific language. For "population group," some Native Hawaiians and Pacific Islanders expressed a preference for being able to select "Native Hawaiians" or "Pacific Islanders" only.

Following suggestions from our previous American Indian and Alaska Native evaluation, we added a search within the Asian American, Native Hawaiian, and other Pacific Islander section. None of the interviewees used the search text box that was specifically for searching within this section (see figure 1). Some complained that they did not see it

because it was below the fold. Others thought that the search text box at the top and the one for the Asian American, Native Hawaiian, and other Pacific Islander section were identical. Part of the problem was that the instructions for using the A-Z list were underneath the search text box, so people were associating the instructions to the search text box. However, once they knew about this feature, they were all glad it was available.

Goal 5: To understand how healthfinder® can best serve intermediaries of Asian American, Native Hawaiian, and other Pacific Islander communities.

- Validate approach of an English searchable database of multilingual patient education materials for Asian American, Native Hawaiian, and other Pacific Islander intermediaries.

Intermediaries were asked the question, "How can healthfinder® best serve Asian American, Native Hawaiian, and other Pacific Islander populations?" Most respondents were very pleased that ODPHP was conducting these interviews and consulting with community groups. They were especially pleased to learn of a central location where they can go for translated materials.

> This is fantastic. This is good. I've been wanting something like this since 1987. This is really nice.
>
> —Emilie Dearing, National Asian Pacific American Families Against Substance Abuse

> I think what you have is really good and would really help, but unless they [Asian American, Native Hawaiian, and other Pacific Islander populations] have the mechanism to access the information, then it's hard to serve them. We have an Internet café with three or four computers at our health center. So if we can get information out on where to access the information that you have, it would be really helpful because it [healthfinder®] does have really good information.
>
> —Kauila Clark, Wai'anae Coast Comprehensive Health Center

> Just try to get some more resources, some more sites. I know it's hard because there aren't that many. But at least you're supplying the information here. You're making it simpler, too. They can just go right to a certain site for specific information and that's good. I like this site. In fact, I've already bookmarked it.
>
> Marion Hannemann, Samoan National Nurses Association

Our approach of creating an English-language searchable database of translated materials was similar to successful models developed by other international organizations. MultiLingual-Health-Education.net (MLHEN), developed in Canada, identified the need for a coordinated effort to address translation needs in 1995. The project gathered all the health-related translated materials used by the 22 health care agencies involved in the partnership. MLHEN's translated materials are designed for the general public to use with the help of health care professionals, particularly in multicultural settings where translations of quick and reliable health-related information are needed. (See http://www.multilingual-health-education.net.)

The Multicultural Health Communication Service, developed in Australia, provides information and services to help health professionals communicate with non-English-speaking communities throughout New South Wales. This organization has more

than 450 publications available in a wide variety of languages. (See http://mhcs.health.nsw.gov.au/health-public-affairs/mhcs/index.html.)

The main concern expressed by intermediaries is the disaggregation of Native Hawaiians and other Pacific Islanders from Asian Americans. However, most agreed that we had to start somewhere. It was better to include Native Hawaiians and other Pacific Islanders than not have any resources for them.

> You have to start somewhere, right? If I'm an intermediary and thinking what I need most is to find out where do I go for help or if I have a client that I'm trying to find information for, then I can come here.
>
> —Hardy Spoehr, Papa Ola Lakahi

In terms of content, the top health topics requested were traditional healing, diabetes, mental health, HIV/AIDS, cardiovascular disease, cancer, access to care, hepatitis B and C, nutrition, and tuberculosis. For Native Hawaiians and Pacific Islanders, obesity and hypertension were additional topics of importance. One intermediary described how important it was in his work to find or provide information on traditional healing.

> If you have a cold or a very low fever, especially with a cold and coughing, they rub your skin with a coin. They call it "coining" in English because they sometimes use a quarter and some special oil and they pretty much rub your skin. They leave big bruises on your skin and they believe it heals . . . and it does heal the cold. We have hundreds of calls from schools because children go back to school after having a cold with very large bruises on their neck or their back. It looks like they have been beaten up by their parents. I think for the past 10 years, we have been slowly educating ourselves and the schools that this is a form of traditional healing among the Southeast Asian families.
>
> —Vaka Faletau, County of Los Angeles, Asian Pacific Project

Section 6
Recommendations

This section provides general recommendations based on the research results. Recommendations specific to healthfinder® are not included.

Recommendations Regarding Translated Materials

Intermediaries recommended that Federal agencies develop a lexicon or glossary of terms for health words for each Asian American, Native Hawaiian, and other Pacific Islander language. In addition, Federal agencies should provide guidelines, standards, or a process for creating quality online translated materials.

> Think through what you are translating. Often times there are Web sites or phone numbers that are translated. If you are going to translate it, think through how people will respond. They will call this number or go to this Web site. But what if the Web site is only in English and the 1-800 number is only answered by an English-speaking person? If you have language capacity, say so. If you don't, you could add that callers will need an English speaker to call for them. I think there is often an assumption that you can just take the English piece and just automatically translate. But you actually need to go through and think about if you were in a non-English reader's shoes and looking at this. What would I end up experiencing?
>
> It is important to do focus group testing even before the messages are developed, preferably in the native language. Being able to get that input before you start is important because I think it's often difficult once you already have it set in English to expect the translated version is going to automatically work with the target community. If possible, focus group test the materials after they have been translated. So basically, get the folks that are supposed to be benefiting from these materials involved with the materials development. Find out if your messages make sense and if your information addresses the needs of the community you're trying to reach.
>
> If you are working with translators, you want to be able to develop your own lexicon or glossary. Otherwise, different translators will come up with their own translations for terms and concepts that don't have a standard translation. Different documents with different translations can end up defeating your purpose by confusing your readers.
>
> Then another practical thing is just to recognize that there is an expansion of text when it comes to translation. Folks need to think about expanding the format or cutting out some information instead of just making the font size smaller.
>
> —Linda Okahara, Asian Health Services

The following three resources offer examples of guidelines, standards, and translation services used by other organizations:

- NSW Multicultural Health Communication Service in Australia offers translation guidelines and checklists. (See http://mhcs.health.nsw.gov.au/health-public-affairs/mhcs/index.html.)
- The Minnesota Department of Health developed the *Translation Protocol: A Guide to Translating Materials for Limited English-speaking Communities,*[28] which covers checklists, examples of translations that have gone wrong, lists of qualified translation agencies, and how to find a qualified translator. (See http://www.health.state.mn.us/communityeng/multicultural/translation.pdf.)
- The Interagency Working Group on Limited English Proficiency offers a clearinghouse of information, tools, and technical assistance for Federal agencies, recipients of Federal funds, and community-based organizations and individuals regarding meaningful language access to Federal and federally assisted programs and activities. (See www.lep.gov).

The following examples, taken from the Minnesota Department of Health's *Translation Protocol*, offer a humorous look at translations gone awry, while underscoring the importance of accurate translation.

- The name Coca-Cola in China was first rendered as Ke-kou-ke-la. Unfortunately, the Coke company did not discover until after thousands of signs had been printed that the phrase means "bite the wax tadpole" or "female horse stuffed with wax" depending on the dialect. Coke then researched 40,000 Chinese characters and found a close phonetic equivalent, "ko-kou-ko-le," which can be loosely translated as "Happiness in the mouth."
- In Taiwan, the translation of the Pepsi slogan "Come alive with the Pepsi Generation" came out as "Pepsi will bring your ancestors back from the dead."
- Also in Chinese, the Kentucky Fried Chicken slogan "finger-lickin' good" came out as "eat your fingers off."
- The American slogan for Salem cigarettes, "Salem—Feeling Free," got translated in the Japanese market into "When smoking Salem, you feel so refreshed that your mind seems to be free and empty."

For online translated materials, interviewees recommended providing users several options, ranging from PDFs to graphical displays to entire Web sites that require a language plug-in for browsers. Intermediaries also suggested developing bilingual materials to prevent English-language documents from being separated from their translations.

Recommendations Regarding the Use of Visuals

For the Web site or printed materials, intermediaries recommended using photographs of Asian Americans, Native Hawaiians, and other Pacific Islanders living in America. Many confided that they would rather throw away than distribute free materials that they felt were inappropriate for their community. Interviewees suggested that agencies either contract with Asian American, Native Hawaiian, and

[28] Minnesota Department of Health, Communications Office. *Translation Protocol: A Guide to Translating Materials for Limited English-speaking Communities* (St. Paul: Minnesota Department of Health), November 2000. Available online at http://www.health.state.mn.us/communityeng/multicultural/translation.pdf.

other Pacific Islander intermediary organizations to produce their materials or contact them for photographs or graphics. They were very pleased that ODPHP asked for their opinion and review prior to finalizing and printing materials. In addition, intermediaries recommended translating quality audiovisual materials for their communities.

> I'd like to see some collaborative effort to take quality patient education materials that are audiovisuals and translate them for nonreading or nonliterate people, especially for cultural groups that are immigrants. It's nice if we could have something that can be played back on a computer screen and even distributed on CD-ROMs as well so that they could be distributed. I've just heard over and over again that pictures are really important. The overall health literacy issue is such that the reading level and pictures of patient education materials needs to be brought down to what people can use.
>
> —Margaret Allen, Hmong Health Information Promotion Project

Recommendations Concerning Usability

Some general usability issues that suggested a need for further testing, as demonstrated by the following concerns expressed by intermediaries:

- Some users were inexperienced or annoyed with PDF files. Users need to be warned that a link will open a PDF file.
- Some users did not have a language plug-in installed for their browser. Users need to be warned that they need a plug-in to view the site properly.
- Many users desire more choices for sorting the information presented.
- Some labels or links were not descriptive enough to match user expectations.
- Providing more instructional content on sites would help users determine where to go to get the specific information they are seeking.

Recommendations for Asian American, Native Hawaiian, and Other Pacific Islander Online Health Information

Intermediaries recommended that the next phase of the project address the following user preferences:

- Disaggregate Native Hawaiians and other Pacific Islanders from Asian Americans at the very least. The best scenario would be to have a separate section for each of these three groups.
- Review the quality of the translated materials that the site links to. Many interviewees would like to know how the materials are rated or reviewed.
- Provide access to local organizations. Most intermediaries get calls from community members wanting to know how to access health services in their area.

> I do get calls from around the country like, "do you know of anything in St. Paul?" And if I can't find it pretty easily on the Internet, then I'll just tell them to call the health department over there only if I know someone there.
>
> —Gem Daus, Asian and Pacific Islander American Health Forum

Local resources—If that is possible, that would be superb. So if I lived in Chicago, I would know where to go in Chicago for culturally competent mental health treatment or services. It would be nice to know which organizations are service providers.

—Dr. DJ Ida, National Asian American Pacific Islander Mental Health Association

Section 7
Conclusion

> For the purpose of designing cultural usability, we will keep the definition simple and operational. We will view culture in terms of attributes belonging to a target audience that distinguish it from other target communities. Therefore, we view culture as the collective of identifiable behaviors, practices, conventions, signs, symbols, artifacts, values, and beliefs that characterize a group. The practice of cultural usability requires that the designer identify the target audience's relevant attributes and design accordingly for them.
>
> —Albert N. Badre[1]

ODPHP studied "cultural usability" as defined by Badre for 2 of the 15 special population sections of www.healthfinder.gov:

- American Indians and Alaska Natives
- Asian Americans, Native Hawaiians, and other Pacific Islanders.

In our investigation of Asian American, Native Hawaiian, and other Pacific Islander populations, ODPHP gathered significant information about various audiences, attributes of health information that are important to these audiences, and their reasons for visiting health-related Web sites.

ODPHP validated the approach of an English searchable database for intermediaries of Asian American, Native Hawaiian, and other Pacific Islander populations. They were interested to learn there is a central location where they can go for quality translated materials. They shared with ODPHP their frustrations about the lack of such materials. Intermediaries recommended that Federal agencies consider developing a health or medical lexicon or glossary as well as standards or procedures for translating materials.

As more materials are collected for these audiences, intermediaries suggested that separating Asian Americans, Native Hawaiians, and other Pacific Islanders into three distinct categories ultimately provide the best service to each of these communities.

The tools presented in appendix B and appendix C are designed to be building blocks or foundations for better understanding what Asian American, Native Hawaiian, and other Pacific Islander intermediaries want to accomplish on healthfinder® and other health information Web sites.

Appendix A
Intermediaries Who Provided Comments

Interviewed Intermediaries

Margaret Allen, M.L.S.-A.H.I.P.
Library Consultant
Hmong Health Information Promotion Project
Northern Wisconsin Area Health Education Center

Rich Bettini, M.P.H., M.A.
Executive Director
Waiʻanae Coast Comprehensive Health Center

Jeff Caballero, M.P.H.
Executive Director
Association of Asian Pacific Community Health Organizations

Adela Calbillo, M.L.S.
Consumer Health Librarian
Houston Academy of Medicine—Texas Medical Center Library

Christine Chen
Executive Director
Organization of Chinese Americans

Dr. Ming-Hui Chen, M.D.
Former Medical Director
South Cove Community Health Center

Dr. Simon Choi, Ph.D.
Director of MPH Program
University of Kansas Medical Center

Mary Chung, M.B.A.
Founder
National Asian Women's Health Organization

Kauila Clark
Consultant and Traditional Healer
Second Vice President
Waiʻanae Coast Comprehensive Health Center

Gem Daus, M.A.
Legislative and Governmental Affairs Coordinator
Asian and Pacific Islander American Health Forum

Emilie Dearing, R.N., M.S.N., C.S.
Chair and Nurse Consultant
National Asian Pacific American Families Against Substance Abuse

Dr. Butch de Castro, Ph.D., M.S.N./M.P.H., R.N.
Chair
American Public Health Association, Asian Pacific Islander Caucus

Vaka Faletau, M.S.
Social Worker
County of Los Angeles Department of Children and Family Services, Asian Pacific Project

Abhijit Ghosh, M.P.H.
President
South Asian Public Health Association

Marion Hannemann, R.N.
Executive Director
Samoan National Nurses Association

Lisa Hasegawa, M.P.H.
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Appendix B
Audience Personas

ODPHP met with 30 Asian American, Native Hawaiian, and other Pacific Islander intermediaries representing target populations (organized according to the context in which they might use the Internet to find health information).

- Executive directors
- Health educators and social workers
- Legislative analysts
- Librarians
- Physicians and nurses
- Program administrators
- Researchers
- Traditional healing practitioners

The purpose of a persona is to create sample audiences that can be compared against each other in crafting electronic documents to suit many audience needs. User-experience research refers to persona development as a "necessary foundation of good interaction design."[1] The purpose of the persona is not to provide information on a specific person; instead, personas serve as hypothetical archetypes of actual users. The personas developed in this study are defined based on the experiences of the interviewers.

Executive Directors

Typical executive directors oversee nonprofit organizations that provide either direct health care or infrastructure to community-based organizations. They are highly educated, holding at least one advanced degree. Ranging in age from their mid-30s to age 70, they engender a great deal of respect from community members as well as influence on a national level.

Typical executive directors access the Internet both at the office and at home, up to 5 hours per day. They spend the majority of their workweek answering e-mail, calling various partners, going to meetings and traveling. Usually, they do not spend a lot of time surfing the Internet.

The top five tasks that executive directors try to accomplish on a health information Web site are:

1. Search for statistics
2. Find grant information
3. Find information on health specific to communities
4. Find updates on health news
5. Gather information for a meeting

[1] A good introduction to personas in user-experience research can be found in Alan Cooper, *The Inmates Are Running the Asylum: Why High-Tech Products Drive Us Crazy and How to Restore the Sanity*, Sams Publishing, 1999.

The most rewarding aspect of executive directors' jobs are making a difference, empowering community members to do what they are capable of, teaching others as well as learning from mentors, and strengthening the capacity of the community.

The most challenging aspects of their job are having limited resources, having limited data, handling administrative issues, and breaking down language and cultural barriers that prevent community members from getting the health care they need.

Health Educators and Social Workers

Typical health educators and social workers work directly with community members, referring them to treatment or providing counseling. Some develop health education curricula, translate health education materials, conduct outreach to the community, or manage other staff.

Typical health educators and social workers access the Internet mostly at the office and sometimes at home. Because they are often seeing clients, they spend up to 1 hour a day on the Internet. Social workers have even less time than health educators to access the Internet because they are often visiting clients in their homes. Health educators have to develop translation standards and processes because they usually have to provide health education materials that are specific to a particular language and culture. The two professions share the job of assisting community members with accessing services.

The top five tasks that health educators and social workers try to accomplish on a health Web site are:

1. Provide information to individuals or groups (tie)
1. Find information on health specific to community (tie)
2. Find information on disease or condition (tie)
2. Print handouts for patients (tie)
2. Search for statistics (tie)

The most rewarding aspect of health educators' and social workers' jobs are seeing how their health education materials have made a difference for non-English-speaking clients or community and helping clients access services.

The most challenging aspect of their job is sustainability, limited data, and making sure the community voice is heard.

Legislative Analysts

Typical legislative analysts spend their time working on testimonies, briefs, presentations, or staffing a political person. They are highly educated, holding at least a college degree. The average age is in the mid-30s.

Typical legislative analysts access the Internet at the office and at home, up to 4 hours a day. Their workday can be up to 10 hours long.

The top five tasks that legislative analysts try to accomplish on a health Web site are:

1. Gather information for a meeting
2. Find updates on health news (tie)
2. Search for topic related to health care organization (tie)
3. Find information on health specific to communities
4. Find journal articles

The most rewarding aspects of legislative analysts' jobs are the variety of people they meet and the intellectual stimulation.

The most challenging aspects of their jobs are repeating the same thing over and over and setting their priorities.

Librarians

Typical librarians who work on behalf of Asian American, Native Hawaiian, and other Pacific Islander issues are consumer health librarians. They are usually in charge of developing paper or electronic kiosks or Internet sites for people who speak Asian American, Native Hawaiian, and other Pacific Islander languages. They usually hold an advanced degree in library sciences and are not Asian American, Native Hawaiian, and other Pacific Islander.

Typical librarians access the Internet at the office and at home, up to 5 hours a day. Sometimes they staff a reference desk and answer consumer health questions and perform literature searches for physicians. Usually, they are in charge of collecting or creating translated materials in Asian American, Native Hawaiian, and other Pacific Islander languages for paper or electronic kiosks or Internet sites.

The top tasks that librarians try to accomplish on a health Web site are:

1. Search for translated materials (tie)
1. Find journal articles (tie)
2. Search for statistics (tie)
2. Find organizations that on work on a specific issue (tie)
2. See how many Asian American, Native Hawaiian, and other Pacific Islander sites are available (tie)
2. Find information on health specific to communities (tie)
2. Find information on treatment and management (tie)
2. Provide information to individuals or groups (tie)
2. Find information on disease or condition (tie)

The most rewarding aspects of librarians' jobs are serving as a reference point for people and helping them with a health care issue.

The most challenging aspect of their job is collecting or translating materials for Asian American, Native Hawaiian, and other Pacific Islander populations. They have had to create their own translation standards or processes. The projects take much longer than they anticipate, and they face many language and cultural barriers because they are not Asian American, Native Hawaiian, and other Pacific Islander.

Physicians and Nurses

Typical physicians and nurses wear many hats—from providing health care to patients to teaching students to consulting on public health projects. Physicians also

can serve as medical directors of community health centers. They all hold advanced degrees and range in age from their 30s to their 60s.

Typical physicians and nurses access the Internet at the office and at home, up to 4 hours a day. If they are working at a community health center, few physicians and nurses have an Internet connection. They are busy seeing patients, coordinating meetings, teaching medical students, developing mentorship programs, and serving on various organization boards.

The top five tasks that physicians and nurses try to accomplish on a health Web site are:

1. Find information on disease or condition
2. Search for statistics
3. Print handouts for patients (tie)
4. Find information on treatment and management (tie)
3. Provide information to individuals or groups (tie)

The most rewarding aspects of physicians' and nurses' jobs are being able to "educate our community and respect their voices" and bringing those voices into academic centers or government. Of course, they all enjoy the patient interaction.

The most challenging aspect of their job is overcoming barriers like access to health care, limited resources, and language and cultural issues.

Program Administrators

Typical program administrators have a wide range of responsibilities from managing staff to developing Asian American, Native Hawaiian, and other Pacific Islander print and electronic health education materials to evaluating Asian American, Native Hawaiian, and other Pacific Islander public health projects. Some provide direct services to community members who may call them to request health information or services.

Typical program administrators access the Internet at the office and at home, up to 10 hours a day. They are online frequently because they are usually tasked with locating information on behalf of the community or their organization.

The top five tasks that program administrators try to accomplish on a health Web site are:

1. Provide information to individuals or groups (tie)
1. Gather information for a meeting (tie)
2. Search for statistics
3. Find journal articles (tie)
3. Find information on health specific to community (tie)

The most rewarding aspects of program administrators' jobs are "connecting with people" and delivering health information to the community.

The most challenging aspects of their jobs are limited resources and learning new technologies.

Researchers

Typical researchers wear many hats ranging from teaching students to conducting research to holding leadership positions in community organizations. They are highly educated, holding advanced degrees. The average age is in the mid-30s.

Typical researchers access the Internet at the office and at home, up to 4 hours a day. They spend a lot of time preparing for lectures or conducting research on behalf of Asian American, Native Hawaiian, and other Pacific Islander communities.

The top five tasks that researchers try to accomplish on a health Web site are:

1. Find journal articles
2. Find information on disease or condition
3. Search for statistics
4. Gather information for a meeting (tie)
4. Find grant information (tie)

The most rewarding aspect of researchers' jobs is making a difference for students or community members by providing them the information they need to be successful.

> *I see my work as a long-term thing. I don't expect to see the result within a year but the fact that I'm going to a community asking people tough questions and trying to make them realize through the research process that it's not okay to accept the status quo. I try to teach my students the same thing every day, trying to make them aware of health disparities.*
> *~Dr. Mei-ling Wang, Professor, University of the Sciences, Philadelphia*

The most challenging aspect of their jobs is limited resources as well as social, political, and cultural barriers because of politics or discrimination.

Traditional Healing Practitioners

Typical traditional healing practitioners perform acupuncture, Native Hawaiian traditional healing, T'ai Chi, coining or cupping (use of cuplike suction devices to draw "bad wind" from the body), or other forms of Asian American, Native Hawaiian, and other Pacific Islander traditional healing for their patients. They are highly educated, usually holding multiple advanced degrees. They wear several hats—serving on organizational boards, consulting, conducting research, and teaching.

Typical traditional healing practitioners access the Internet at home and at the office, up to 3 hours a day. They are more Internet-savvy than their American Indian and Alaska Native colleagues in the traditional healing arena. This could be due to the fact that most of them are trained in both traditional Asian American, Native Hawaiian, and other Pacific Islander and Western education. This allows them to operate in both worlds and facilitate partnerships.

The top five tasks that traditional healing practitioners try to accomplish on a health Web site are:

1. Find information on traditional healing (tie)
1. Find information on alternative nutrition (tie)
2. Find information on disease or condition
3. Search for topic related to health care organization
4. Find grant information

The most rewarding aspects of traditional healing practitioners' jobs are helping patients feel better, especially when conventional medicine has failed, and helping people find their mission in life.

The most challenging aspect of their job is "trying to come up with creative solutions to problems that have traditionally plagued humanity."

Appendix C
User Task Matrix

Intermediaries rated tasks on a scale of 0 to 3, 0 being that they would never try to accomplish this task on a health information Web site and 3 being that they always will try to accomplish this task on a health information Web site.

TASKS	Health Educators/ Social Workers	Executive Directors	Librarians	Legislative Analysts	Traditional Healers	Physicians/ Nurses	Researchers	Program Administrators	TOTAL	AVERAGE
Find information on disease or condition	2.09	2.00	2.00	1.83	2.67	2.67	2.63	1.92	17.81	2.23
Search for statistics	2.00	2.57	2.00	1.50	2.00	2.44	2.38	2.23	17.12	2.14
Find information on health specific to communities	2.36	2.36	2.00	2.00	2.00	2.00	1.88	2.15	16.75	2.09
Find journal articles	1.73	1.71	2.50	1.83	1.67	2.00	3.00	2.15	16.60	2.07
Provide information to individuals or groups	2.36	1.93	2.00	1.33	2.00	2.22	2.00	2.31	16.16	2.02
Find grant information	1.00	2.50	1.50	1.50	2.33	1.89	2.25	1.77	14.74	1.84
Gather information for a meeting	1.73	2.07	1.00	2.33	1.00	1.89	2.25	2.31	14.58	1.82
Find updates on health news	1.91	2.14	1.50	2.17	0.67	1.89	2.13	1.92	14.32	1.79
Find organizations who work on specific issue	1.91	1.71	2.00	1.17	1.33	1.78	2.00	1.77	13.67	1.71
Search for topic related to health care organizations	0.73	1.79	1.50	2.17	2.33	1.56	1.25	1.54	12.86	1.61
Find information on treatment and management	1.18	1.43	2.00	0.83	1.67	2.22	1.75	1.31	12.39	1.55
Search for translated materials	1.36	1.36	2.50	0.83	1.33	1.56	1.25	1.85	12.04	1.50
Find information on traditional healing	1.09	1.50	1.50	1.33	3.00	1.22	1.50	0.77	11.92	1.49
See how many Asian health sites are available	1.55	1.50	2.00	0.83	1.00	1.67	1.00	1.38	10.93	1.37
Find clinical symptoms	1.27	1.36	1.00	0.50	2.00	2.00	1.63	0.92	10.68	1.33
Determine health risks	1.27	1.57	0.50	1.33	1.33	1.56	1.75	1.27	10.59	1.32

TASKS	Health Educators/ Social Workers	Executive Directors	Librarians	Legislative Analysts	Traditional Healers	Physicians/ Nurses	Researchers	Program Administrators	TOTAL	AVERAGE
Find "user-friendly" summaries on studies	1.00	1.86	0.50	1.33	1.00	1.78	1.63	1.46	10.55	1.32
Print handouts for patients	2.00	1.14	1.50	0.33	0.67	2.22	1.63	0.92	10.41	1.30
Find information on exercise	1.00	1.21	0.50	0.67	1.67	1.67	1.50	0.92	9.14	1.14
Search for stress information	0.91	1.21	0.50	1.00	2.00	1.33	1.25	0.92	9.13	1.14
Find strategies on mental and spiritual wellness	0.91	1.57	0.50	1.00	2.00	1.00	1.50	0.62	9.10	1.14
Find information on alternative nutrition	0.27	0.93	1.00	0.67	2.67	1.33	1.50	0.69	9.06	1.13
Find information on drugs	1.27	1.57	1.50	0.33	0.33	1.56	1.25	0.92	8.74	1.09
Find information on reactions to medications	0.64	1.14	1.00	0.67	1.67	1.22	1.38	0.77	8.48	1.06
Search for environmental health issues	0.73	1.43	0.50	1.00	1.00	1.22	1.38	1.08	8.33	1.04
Find differential diagnosis	0.45	1.07	1.00	0.33	1.67	1.67	1.13	0.38	7.70	0.96
Look up information about doctors and institutions	0.55	1.14	1.50	0.33	0.67	1.56	1.25	0.69	7.69	0.96
Find information on herbs	0.45	1.00	0.50	0.83	1.33	1.11	1.25	0.69	7.17	0.90
Compare traditional to Western ways	0.36	1.14	0.50	0.50	1.33	1.22	1.25	0.62	6.93	0.87
Hear testimonies from others	0.64	1.00	1.00	0.50	1.00	1.11	1.13	0.46	6.83	0.85
Research clinical trials	0.45	0.93	1.00	0.00	1.00	1.56	1.00	0.46	6.40	0.80
Find which tests to order	0.36	0.93	0.50	0.50	0.33	1.78	0.50	0.31	5.21	0.65
Find recalls on medications	0.09	0.93	0.50	0.00	0.33	1.00	0.50	0.15	3.51	0.44